

Psychiatric Social Work Consultations for Persons with Neurological disorders in a Tertiary Care Hospital during COVID-19 Lockdown: A Retrospective Observational Study

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ABSTRACT

Background: Worldwide, COVID-19 pandemic lockdown lead to disruptions of general health services and neurological services in particular. Hence, it is essential to report to the scientific community regarding the nature and range of psychiatric social work services provided for neurology patients during the pandemic lockdown. **Aim:** To study the profile of patients availed psychiatric social work (PSW) consultation during pandemic lockdown at neurology in-patient setting. **Materials and Methods:** The study was retrospective in nature. Data were analysed from an in-patient referral registry. For the study purpose, neurological patients referred from April 2020 - June 2020 were considered. All patients referred for psychiatric social work consultations were included in the study. The study was carried out in tertiary care teaching hospital. Frequency and percentages were used to analyse the data. **Results:** The diagnostic profile revealed Stroke (40%), Guillain-Barré syndrome (10%), meningitis (10%), autoimmune encephalitis (4%), and demyelination (4%), other chronic neurological disorders (30%). Common psychiatric social work services provided were casework with caregivers and patients regarding education about the illness, breaking the bad news, grief interventions, supportive therapy, addressing child care issues, ensuring medication compliance and follow-up services, pre-discharge counselling, assessing socio-economic condition to facilitate financial assistance towards concession in hospital charges, facilitating social welfare benefits, and tracing the family members. **Conclusion:** Stroke, Guillain-Barré syndrome, neuro-infections were the most common neurological disorders required psychiatric social work consultations. Educating the patient and their family about the illness, facilitating welfare benefits and financial assistance were the most common psychiatric social work services provided during the covid-19 pandemic lockdown.

Keywords: Medical social work, service utilization, neurological care, covid-19

INTRODUCTION

Covid-19 is a severe threat to public health. It has affected 25.5 crore people and caused 50.1 lakh deaths worldwide.^[1] In India, 3.45 crore people were affected, out of which 4.64 lakh people died. The mortality rate was 1.1% in India.^[2] Covid-19 is an infectious respiratory illness caused by the severe acute respiratory

Syndrome. Coronavirus primarily transmitted through human to human by droplets. There have been three major corona virus disease outbreaks in 2002, 2012 and 2019.^[3] WHO declared Covid-19 as a pandemic on 11th March 2020. There is no proven treatment for Covid-19; symptomatic treatment is given to the affected individuals.

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Covid-19 lead to disruptions of health services in general and neurological services in particular. It has driven a rapid re-organisation of health care services, affecting clinical care for patients with chronic neurological diseases. Lockdown was imposed to restrict people's movement to contain the rapid spread. There were no public transport facilities such as buses, trains, and flights. Hence, there was no means to access the health care facilities by using the public transport system. However, certain essential services were allowed to function and exempted from complete closure, such as hospitals, pharmacies, and other essential transport services.

Worldwide one billion people are affected by neurological conditions.^[4] About 30 million people suffer from neurological disorders (excluding neuro-infections and traumatic injuries) in India.^[5] The largest contributors of neurological DALYs in India is Stroke (37.9%), headache (17.3%), epilepsy (11.3%), cerebral palsy (5.7%), encephalitis (5.3%).^[6] Considering the magnitude of the problem and highly infectious nature of the covid-19 infection, delivering health care during a pandemic was challenging for both COVID-19 affected individuals, as well those with other acute and chronic neurological conditions.

The available human resource to treat neurological conditions in low and middle-income countries were inadequate. Presently, there are only 1,200 neurologists registered with the Indian Academy of Neurology in India.^[7] Few hospitals employ social workers in neurology settings such as NIMHANS, Bangalore, AIIMS, New Delhi, JIPMER, Pondicherry, SCTIMST, Trivandrum, Vimala Medical College, Thrissur, St. Johns Medical College, Narayana Health city, Bangalore and CMC, Vellore. Presently NIMHANS has two psychiatric social work consultants, two psychiatric social workers, two psychiatric social work trainees posted in neurology. Most neurological disorders are affecting the patients' day-to-day functioning, making them dependent for ADL. Sudden onset of the neurological illness, disabling nature, and lack of awareness about the disease conditions among patients and family members would have made them seek neurological consultation during the complete lockdown. Patients who sought neurological consultation from other states such as West Bengal, Bihar,

and other faraway states got stranded in Bangalore.

Lockdown affected persons with neurological disorders in terms of continuity of care, follow-up, physiotherapy and neuro-rehabilitation services. Worldwide, Covid-19 caused a shortage of medical supplies such as personal protective equipment (PPE), beds, and staff. The covid-19 pandemic has altered neurological health care delivery in many ways. Many neurological patients received tele-consultation and telephone follow-ups. Studies indicate that people from marginalised and poor socioeconomic status have been severely affected during the pandemic. Black race patients faced more mortality and morbidity due to stroke.^[8] Patients hospitalised with covid-19 at non-academic medical centres had worse outcomes than those at academic medical centres.^[9] Patients with Parkinson disease, those with lower incomes had worse access to health care.^[10]

Neurological services were disrupted mild (26%) to moderate (30%), and complete (13%) in 43 countries. The most affected services were neuro-rehabilitation,^[11] neurology emergency care. The most cited reason for the disruption of neurological services was travel restriction and closure of services. Medicines were distributed using a novel approach, and disruption services were mitigated by telemedicine. Cross-sectoral services for neurological disorders such as community-based services, residential long-term care, day-care, special school educational programmes for children, interventions for caregivers, and services by non-governmental organisations were most disturbed, followed by emergency and acute care. The degree of disruption of health services was moderate in most studies.^[12] Covid-19 pandemic affected neurology workflow in four areas: in-patient care, out-patient care, research.^[13] Parkinson's patients with a lower income had more significant difficulties in getting medications and physiotherapy, tele-consultation, digital divide, structural barriers in health care.^[14]

The causes of disruptions in health care services during the pandemic are (1) closure of out-patient services as per Government order; (2) decrease in out-patients visiting the hospital (3) non-availability hospital beds (4) insufficient staff to provide services due to quarantine/self-isolation (5) clinical staff

shifted to provide Covid-19 management or emergency care; (6) insufficient personal protective equipment (PPE) to provide services; (7) disruption of supply chains resulting in unavailability essential medicines, medical diagnostics (8) travel restrictions hindering access to a health care facility for patients (9). Other reasons.^[15]

Preparation of a functional re-organisation plan, strategies for hospitalisation and emergency care, telephone consultations, providing care at a unit outside the hospital for priority patients, and periodical in-patient treatments, and the use of telephone service for patients with epilepsy were the operative decisions taken for providing neurological care during the COVID-19 pandemic.^[16] In Pakistan, there was less admission in neurology, PCR tests were done less than 50% in the hospital before admission in neurology wards, 45% of hospitals started tele-health services for clinically stable neurology patients, 72% of hospitals reduced the number of attendants accompanying neurology patients.^[17]

Nearly half of the patients reported that overall care of their neurological disease during the pandemic was inappropriate, substantial delay in accessing neurological care, information received about the impact of COVID-19 on their neurological disease insufficiently reliable, one-fourth experienced longer waiting times to consult neurologist after lockdown, and deterioration in their psychological well-being, delay in clinical trials and disinvestment in neuroscience research.^[18] There was limited access, hospital visits were allowed for patients' relatives and increase in email correspondence and phone calls by neurology out-patients enabling telemedicine to reach them.^[19]

Given the magnitude of problem and disruption of health care services the study aimed to examine the pattern of psychiatric social work consultations for persons with neurological disorders during covid-19 lockdown. This paper reports nature and range of psychiatric social work services, provided at neurology department during the complete lockdown.

MATERIALS AND METHODS

The study was retrospective observational in nature. A retrospective chart review was used.

Data were analysed from a neurology in-patient referral registry maintained by the psychiatric social work team. Patients referred from three neurology units during lockdown from April 2020 to June 2020 were considered for the study purpose. Lockdown in India commenced on 24th March 2020 and lasted till 30th June 2020. The data was gathered from a referral registry during August 2020. All the patients who received psychiatric social work consultations during the lockdown period were included. Persons who received more than one psychiatric social work consultation were considered as one patient for counting the number and reducing the potential source of bias. Missing data were cross verified with patients' files available in the medical record department. The study was conducted at the tertiary care neuroscience teaching hospital in Bangalore. There are six units in neurology. About 92 patients referred for psychiatric social work consultations from three neurology units were considered. Frequency and percentages were used to describe the data.

RESULTS

Table 1: Socio-Demographic profile

Socio-Demographic Variables		<i>f</i> n=92	%
Gender	Female	46	50
	Male	46	50
Age	3-17 years	14	15
	18- 25 years	12	13
	26-45 years	42	46
	46 – 60 years	15	16
	< 60 years	07	08
Marital Status	Unmarried	29	32
	Married	59	64
	Widow (er)	03	03
	Divorced	01	01
Socioeconomic Status	Lower	74	80
	Middle	18	20
Place	Bangalore	35	38
	Other Parts of Karnataka	45	49
	Andhra Pradesh	05	05
	Tamil Nadu	04	04
	Northern states	03	03
Functionality	Independent	12	13
	Partially dependent	28	31
	Dependent	52	57

Table 1 reveals the socio-demographic profile of patients availed psychiatric social work consultations. There were 92 patients referred for psychiatric social work interventions from the neurology male, female medical ward during the covid-19 pandemic. Half of them (50%) were female, and another 50% of them were male. Few (14%) belonged to the paediatric population aged three years to 17 years, nearly half of them belong to productive age group 25-45 years. The majority (64%) were married. The majority (80%) belong to lower socio-economic status. Nearly half of them who availed psychiatric social work services were from Bangalore and 49% were from other districts of Karnataka such as Kolar, Tumkur, Chitradurga, Chikkamagaluru, Davanagere, Doddaballapur, Gulbarga, Hassan. More than half of them (57%) were dependent on activities of daily living.

Table 2: Clinical Profile

Clinical Variables	Category	Frequency n=92	%
Duration of illness in days	1- 2	07	08
	3 - 7	19	21
	8-30	46	50
	31-180	08	09
	181 - 365	03	03
	> 365 days	03	03
Caregiver	Parents	51	56
	Spouse	17	19
	Children	14	15
	Siblings	05	05
	Relatives	03	03
	No caregivers	02	02
Diagnosis	Stroke	40	44
	GB Syndrome	10	11
	Neuro- Infections	14	15
	Neurological conditions	28	31

Table 2 shows the clinical profile of the patients. Half of them (50%) had one week to one-month duration of illness. More than half of the caregivers (56%) were parents who accompanied the patients at the time of lockdown. The patients' diagnostic profile revealed stroke (28%), GBS (10%), autoimmune encephalitis, and demyelination (4%), meningitis (2%), moyamoya disease,

epilepsy, Parkinsonism, Myopathy related to HIV, and other disorders such as myasthenia gravis, pulmonary tuberculosis, and postpartum related neurological disorder (constituted 1%).

Table 3: Psychiatric Social Work (PSW) Consultations during Pandemic Lockdown

PSW Consultations	frequency	%
Social Casework	64	70
Education about illness	47	51
Facilitating welfare benefits for poor patients	39	42
Supportive psychotherapy	27	30
Assisted patients to procure medicines	24	26
Pre-discharge counselling	18	20
Assessment	18	20
Other interventions	09	10
Counselling for medication adherence	06	07
Facilitating UDID registration/ Disability welfare benefits	06	07
Tracing family	05	05
Waiver-off of hospital charges	04	04
Unknown patient management	03	03
Pre-marital counselling	03	03
Motivation enhancement therapy	03	03
Breaking the bad news	02	02
Family therapy	02	02
Telephone follow-up & tele-counselling for out-patients	679	--

Table 3 reveals the psychiatric social work consultations provided during the pandemic lockdown. Psychiatric social work services provided were social casework services(70%), caregiver and patient education regarding illness (51%), assessing socioeconomic condition to facilitate financial assistance to avail concession in hospital charges(20%), supportive psychotherapy (30%), pre-discharge counselling (20%). Other psychiatric social work services provided were telephone follow-up for continuity of neurological care, tele-counselling for patients with epilepsy, crisis interventions, assisted patients in getting medicines, prescriptions using novel methods by referring them to district general hospital, availing online prescription from the treating team to ensure drug adherence.

DISCUSSION

The study profiled the essential psychiatric social work services provided to neurology patients during the covid-19 lockdown using retrospective chart review. The present study reported equal representation from the male and female gender. This finding contrasts previous studies where males outnumbered females in neurology consultations.^[3,20-24]

The age of onset of neurological disorders differs in different neurological disorders. In this study, the majority were 26-45 years of productive age group. This finding was similar to previous studies.^{[3][20][21][24]} Nearly half (44%) of the persons who sought neurological treatment during covid-19 lockdown had a stroke. Owing to the life-threatening nature of the illness, persons with stroke seek treatment immediately. This finding was in concordance with previous studies.^{[3][21][23][25]}

During the pandemic, psychotherapy protocols were revised to have a limited number of sessions and reduced the duration of therapy sessions in our hospital. In this study, supportive psychotherapy was provided to address psychological distress in patient and enhance optimum psychosocial functioning, which was affected due to neurological illness. The family burden was more among those dependent on daily living activities. Patient education was given to patients to have adequate information about their condition, medical procedures, and choices they have regarding treatment. It enables patients to manage their life with disease and optimise their health and well-being. Providing patients with complete information about their illness create an atmosphere of trust, enhances the therapeutic alliance and empowers patients to participate in their health care. Effective patient education ensures that patients have sufficient information and understanding to make informed decisions regarding their care.^{[26][27]}

Supportive psychotherapy is suitable for persons with chronic medical illness to deal with psychosocial issues secondary to their long-standing illness in terms of acceptance, adjustment, anxiety, depression, coping, frustration, anger and relationship issues. The literature described various forms of supportive psychotherapy for chronic medical illness.^{[28][29][30]}

Neurological care was disrupted due to the closure of out-patient service and non-availability of transport due to travel restrictions as per government directives. There was no shortage of personal protective equipments and workforce during the lockdown. Hospital administration arranged alternative transport facilities for the staff commuting within a 30 km radius. Psychiatric social work consultations are provided on a rotation basis and alternate days. Cases were discussed through video conferencing.

Psychiatric social work services, human resources and psychosocial management of neurological disorders were re-organised during Covid-19 from April 2020 to June 2020. It has severely affected the access to neurological consultations for persons with neurological disorders. Remote consultations were provided to psychiatric social work trainees using the technology platform to provide social work intervention to the in-patients and their family members. Psychiatric social workers and trainees provided face-to-face interventions by using masks, face shields and maintaining social distance.

The psychiatric social work practice comprised of investigating the patient and their family needs, providing psychosocial care, tailor-made interventions. During the unprecedented period, schedule was explicitly made for in-patient care and out-patient care. Most of the interventions need the physical presence of the patient and family members, which was changed to brief interventions, and telephonic sessions were utilised for patients who needed intensive therapy. The patient and their family members discussed their fear, anxiety, and distress related to the Covid-19, which was addressed during social casework sessions. Although the number of patients significantly less, the quality of care was provided for each patient. The patients' financial needs were taken care of by the hospital administration.

Social work trainees, psychiatric social workers, and consultants adhered to Covid preventive measures and providing services on a rotation basis. Most patients were provided brief psychiatric social work intervention ensuring minimum possible standard care. Organising the way of rendering psychiatric social work services was changed during the

Covid-19. Health-related anxiety, fear of getting infected were present among the service providers. During the admission, few patients had a Covid infection. There was no incidence of spread of infection from service provider to the patients and vice-versa, patients to other patients during the admission.

The Social Work team had 3-4 members in a month to render the minimum standard psychiatric social work consultations during the lockdown comprising social work trainees, psychiatric social workers and psychiatric social work consultants. During the pandemic, psychiatric social work team had adequate human resources to provide psychiatric social work services. Due to lockdown, all the teaching and training activities were shifted to the online mode. Lack of knowledge about modus operandi and newness to the online medium affected the quality of open discussion in the initial period. The regular practice of online education helped to confront the challenges to a few extent.

The patients concerns were follow-up after discharge as they were unable to get consultations in case of an emergency during lockdown. Few patients and families from lower socioeconomic status struggled to avail welfare benefits available for them. As they were unable to bring below poverty line ration cards to hospital in a crisis situation, and few families were unable to get income certificates from Thasildhar office due to logistic issues. Owing to these difficulties, paying complete hospital charges without any concession was an additional burden on the patient and family during when they lost their jobs. Patients who got discharged from the hospital had to depend on ambulances to reach home as public transportation was stopped.

Challenges Faced

The out-patient department was suspended temporarily when the lockdown was announced. Alternative plans were made to mitigate the disruption of services during pandemic lockdown to address patient requirements, telemedicine services for in-patients and helpline facilities to address the general mental health concerns of the public. However, the emergency and casualty services continued to function. The in-patient wards were operated for patients who got shifted from casualty and emergency services.

Paediatric neurology ward was temporarily closed during lockdown and few children were treated in female neurology ward.

Neurology special wards were closed. The psychiatric social workers and consultants took charge of out-patient follow-up services in neurology through IVRs and 24 x 7 helpline on a routine basis. The last six-month out-patients were pooled from the medical record section for telephonic follow-up. The purpose of telephonic follow-up was to know the present complaints of patients, medication compliance, side-effects of medication, and mental health concerns due to COVID 19.

Patients who required immediate attention were referred to a nearby hospital. An online prescription was given to patients who required an alteration in their medication. Patients who shared their mental health issues and concerns due to the Covid-19 were addressed. They were encouraged to have creative activities inside the house and share their thoughts with others. They were provided the helpline number of NIMHANS and their respective state helpline number to discuss their concerns.

Inconsistency in providing needed interventions had been noticed on account of the sudden discharge, inadequacy of therapy sessions, difficulty to mobilise the local resources, lack of external funds, unavailability of mobility aid and medicines, limited rehabilitation centres for neurological disorders posed difficulty to unknown and abandoned patients.

Problems in access to medication in their locality, few patients, stopped taking medication as they could not afford to buy medication due to a job loss. Many daily wage workers were facilitated to get the free medication available in district government hospitals by showing their discharge summary and prescriptions. Few patients stopped medication as their follow-up was over-due. Hence, they were afraid of continuing medication and its side effects without a proper review. Patients who required physiotherapy had arranged paid physiotherapy services from outside and for few patients caregiver themselves did physiotherapy based on physiotherapists instructions. Many patients shared their psychological distress as living a life of

lockdown due to their illness and disability and further restriction in their limited social life, causing more stressors.

Patients who identified with covid symptoms were isolated in casualty red zone areas. The patient who tested positive from the wards were immediately shifted to covid-ICU. The therapy sessions focused on addressing caregiver concerns as they are not allowed to see the Covid patients. Patients who sought neurology emergency service, Covid-19 protocol guidelines and self-quarantine measures were explained to them. Primary caregivers and older adults were isolated from the ward for one week as they are more vulnerable to getting infected, and alternative care giving plans were considered. Most patients and caregivers were lost their job due to lockdown. Social workers did assessment of their socio-economic conditions and recommended waiver-off of hospital treatment charges for the patients based on their socio-economic status.

There are incidents bystanders brought the patients and refused to stay at the hospital due to anxiety related to covid. Few relatives abandoned the patients at the hospital and went away. Few unknown patients who required long term care were unable to be placed in non-governmental organisations as they stopped taking new patients.

Few difficulties encountered were two in-patients tested positive for covid-19, and the social work trainees were seeing patients next to them. An immediate debriefing session was done with the trainees, and an incident report was sent to the hospital infection control team to know about quarantine procedures. There was a fund shortage to facilitate welfare benefits to all patients as most of patients and their family members lost their jobs.

This study adds information about the psychiatric social work consultations provided in a neurology setting during lockdown. Essential psychiatric social work services were provided during covid-19 lockdown were highlighted. Major diagnostic categories required psychiatric social work services in the neurology setting during the covid-19 lockdown were illustrated. Despite many challenges during the pandemic crisis, the psychiatric social work team continued to provide minimum standard psychiatric social

work consultations to the neurology patients and their families to meet their treatment needs. Allocation of separate budget and adequate funding for the health sector during a disaster would be helpful in treating the patients at free of cost. The patients with a neurological problem who tested positive Covid-19 require a continuum of care.

It was a learning opportunity to work during the pandemic crisis and disaster situation, to provide psychosocial support for the neurology patients and their caregivers, and mitigate the disruptions of psychiatric social work services at neurology.

Limitations

Study results can be interpreted in the limelight of the limited sample size, and results cannot be generalised as the study was conducted during the pandemic lockdown.

CONCLUSION

Persons with Stroke, Guillain-Barré syndrome, neuro-infections were the most common neurological disorders that required psychiatric social work consultations. Educating the patient and their family about the illness, facilitating welfare benefits, and financial assistance was the most common psychiatric social work services during the Covid-19 pandemic lockdown.

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